

CAMBRIDGE RARE DISEASE NETWORK



Kay Parkinson was the mother of two children who were diagnosed with the ultra rare disease Alström Syndrome when they were aged 18 & 15, having had four previous mis-diagnosis. Both children died following heart and heart/kidney transplantations aged 25 and 29 respectively. They received little support or understanding of their rare condition.

Kay qualified as a lawyer in 1996 as a mature student, specialising in charity law. In 1998 she founded the charity Alström Syndrome UK (ASUK). Kay served as their founder/ CEO for 15 years. In 2007 she fought the DOH to gain funding from the NHS Highly Specialised Services for the charity, she held the only UK database on affected families which she had collected since 1998. Kay stepped down in 2013 after ASUK was awarded EURORDIS Patient Organisation of the Year, to start up Alström Europe (AS EU) charity, where she still serves as a Director. In 2015 Kay joined the steering group of Cambridge Rare Disease Network as she believes all rare diseases need to work together for better diagnosis, treatments, services and a much needed higher public profile.

From September 2015 Kay has formally set up and structured Cambridge Rare Disease Network (CRDN) as their CEO. She is enjoying the challenge of working with a novel multi-stakeholder organisation and hopes to form closer links between the Cambridge “Cluster”, the largest biotech’s in Europe, the Cambridge University and people affected by rare diseases.

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